

Family Perceptions on Stressors Present for an Older Adult when Transitioning from the
Community into a Long-Term Care facility

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Abstract

This study examined family perceptions of stressors present for an older adult in transition from the community into a long-term care facility. With the rise of older adults from the “baby boomer generation” moving into long-term care facilities, this study aimed to better understand the circumstances surrounding when an older adult leaves the community setting. During this transition, the family member’s support often plays a role in the stress level for the older adult. This study asked the family members about the overall circumstances that led to the older adult’s transition into the long-term care facility. Family member participants were recruited from a senior community in the Midwestern part of the United States. The family member participants were qualified to be interviewed based on their older adult moving into the long-term care facility in the past three years. Data was collected by administering the *Reintegration to Normal Living Index (RNL)* and *Survey for Identifying Stressors Present for an Older Adult Transitioning from the Community into Long Term Care*. A total of 30 family members participated in the study. Results indicated that family members perceived that older adults experienced stress in the transition into long-term care. Factors that increased stress included not being able to physically care for the self, falls, and decline in mental status. Results also showed that family members perceived that if the older adult was not satisfied with how their self-care needs were met, they were less likely to participate in recreational activities.

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Introduction

Advances in health care combined with the unavailability of family members to fill the role as caretaker, the older adult population transitioning from living independently in the community to long-term care continues to increase within the United States (1). With little to no resources to prepare for this transition of care, the older adult often experiences negative stressors that lead to secondary health complications in addition to the primary health condition (1). Addressing these negative stressors through preventative therapeutic interventions may provide a healthier and more positive transition for the older adult, as well as decrease secondary health conditions. A recreational therapist is able to use knowledge in assessment, planning, implementation, evaluation, and documentation to help create a beneficial environment for participants (2). A recreational therapist can also help older adults living in the community transition into a higher quality of life through therapeutic interventions during the transition process (2). The aim of this study was to determine what stressors are present for older adults in transition from the community into long-term care through the perceptions of a family member.

Specific Aims

1. To determine what stressors are present for older adults in transition from the community into long term care through the perceptions of a family member.
2. To determine the impact transition from the community into long term care has on daily normal living for an older adult from the perceptions of a family member.

Background and Significance

In 2014, 14.5% (46.3 million) of the United States population was age 65 or older and this number is projected to reach 23.5% (98 million) by 2060 (2). Furthermore, Canizares et al. states the large number of aging older adults, including "baby boomers" (born 1945–1964), are generating concerns for the provision of health services in the United States (3). With the baby boomer population living longer, the potential for developing more chronic illnesses including, but not limited to, heart disease, cancer, chronic bronchitis, stroke, dementia, and diabetes mellitus is leading to longer and more advanced health care services. For example, in 2012, 60% of older adults managed two or more of these chronic illnesses (1).

This shift in the increase of the older adult population living longer with health concerns places new challenges on family members and friends who act as caregivers for these older adults. Many times, these caregivers are assisting in activities of daily living for the older adults including, but not limited to, feeding, toileting, dressing, bathing and medication management. In addition, independent activities of daily living such as cleaning, cooking, transportation, and yard work are done with the support of the caregivers for the older adults living in the community. Approximately 25% of U.S. adult population 18 years of age and older have reported providing care or assistance to a person with a long-term illness or disability. Even if these caregivers are family members to the older adult, the stress present in these situations can lead to negative health consequences including stress and depression for both the caregiver and the older adult in transition. Furthermore, these caregivers often need increased personal support to preserve their

own health. These risks are greater for caregivers of older adults with Alzheimer's and related dementias (4, 5).

A point comes where, due to the intensified chronic illnesses, many older adults are not able to continue to live safely in the community, even with the presence of caregivers. A decision was reached by the older adult and/or family members to transition to a long-term care facility. However, this transition can cause much distress, including increased negative stress levels. Additionally, prolonged negative consequences from negative stressors are common for the older adult during this transition process.

Prior research has identified negative stressors older adults experience when transitioning into long term care facilities from the community setting, typically his or her home. One negative stressor discussed is the low level of family support and/or the lack of local family support in the lives of an older adult living in the community (6, 5, 7). Another negative stressor is the number of previous hospitalizations in recent years (8, 9). Callahan et al. elaborates on the connection between re-hospitalizations and transition to a long-term care facility when finding that older adults with dementia who are cared for at home and who transition back to home after a hospitalization often have moderate to severe impairments in function and cognition (8). Furthermore, the negative stressors of limited home health services due to lack of funding or rural location can further lead to transitions into long term care (6, 10). A change in mental status or increase in falls is shown to also be negative stressors in the decision to move to a long-term care facility (11, 12). Perceived wellbeing can additionally be a negative stressor if the older adult identifies with personal decline in health (13, 14). Lastly, the negative stressors of older adults not choosing for themselves to move to a long-term care facility can have lasting detrimental consequences (15, 16, 17, 18).

The purpose of this research study was to survey these negative factors by examining the current transition process into long term care through information gained from family members of the older adult. In many situations, the family members were already appointed as the power of attorney for the older adult by the time this transition takes place from the community into long term care. Therefore, family members of the older adult provided valuable insight into the predicaments and stressors associated with their older adult family member remaining in the community (19). Often the power of attorney helped support the decision for an older adult with cognitive impairments or mental disabilities to move to a long-term care facility (20). The importance of family member's perspective shed new light on the transition for the older adult from the community to long-term care (21, 19). Through these identified negative factors, the outcomes of the transition process can be further studied to address if therapeutic interventions through various modalities could decrease negative stressors and increase quality of life for these older adults in transition to their new home in long-term care. Therefore, the purpose of this study was to receive family member perceptions on what negative stressors are present during the transition. If the negative stressors can be identified then more effective therapeutic interventions could be established in the future to decrease the negative stressors.

Methods

Research Design

A cross-sectional research design was facilitated for this study that included interviewing family members of an older adult who has transitioned from home to long-term care. The current research in the literature review for this study identified current negative stressors experienced

during life transitions that were utilized to develop the interview questions. The Reintegration to Normal Living Index was used to gain insight into caregiver burden on the family members of the older adult in transition (22). The researcher completed all of the interviews with family members. Interviews were conducted over a one-month time period at the senior living center in a suburban city in the Midwest region of the United States of America. The study was approved by the Indiana University Institutional Review Board (IRB) prior to the implementation of the study.

Sampling Procedures

A purposive sample was facilitated for this study, since the purpose was to study family perceptions on negative stressors present for older adults when transitioning from the community into a long-term care facility. Within the location of the proposed study, there were 260 residents who reside at the long-term care facility. The entrance criterion required residents to have "limitations in functional status" (physical, mental or emotional) to live in this long-term care facility.

Subject Recruitment

This study recruited 39 participants from Menorah Park Center for Senior Living in Beachwood, Ohio. Potential survey participants were selected based on the criteria of their family member transitioning into long term care. There were 30 total family member participants who completed the study. The senior center's documentation software program identified a list of older adults who have transitioned into Menorah Park in the past three years. The family member participants were verbally invited to participate by the researcher and given the information packet on the study in person. The senior center's documentation software program was used to locate some demographic information that was collected prior to conducting survey interviews.

Inclusion Criteria

Participants had to be a family member of an older adult who transitioned from the community into a long-term care facility. The family member type had to be in blood relation to the older adult but could vary from spouses, children, parents, or grandchildren. Participants must have had their family member transition to the long-term care facility within the last three years.

Procedures

Upon IRB approval, potential participants were recruited from the senior community in the Northeastern part of the United States. The researcher prioritized invitation to family member participants based on most recent admissions to the long-term care facility in order to maintain data consistency. Once the family member participant agreed to participate in the study, a one-on-one interview of the survey questions was conducted between researcher and family member (refer to Appendix A). All surveys were conducted in a quiet space of the senior living center without the presence of the resident of the family member. All data were collected by the researcher. Data were first collected through verbalizing questions to family member participants and researcher recorded answers on the survey paper. The data were then checked

through carefully inputting into a computer spreadsheet. Data collection took approximately 20 minutes for each individual research participant.

Measurement Instruments

The standardized measurement instrument for this study was the Reintegration to Normal Living Index (RNL) scale (22). The RNL was selected because it assesses the degree to which individuals who have experienced traumatic or incapacitating illness achieve reintegration into normal social activities (22). This instrument had been tested for validity for community dwelling elderly so it was applicable for this study. The RNL was constructed from 11 scales, each of which assesses the degree to which the older adult responds to social activities based on illness or disability. The seven domains of integration included indoor activities, community and distance mobility, self-care, daily activities (work and school), recreational and social activities, family role(s), personal relationships, presentation of self to others, and general coping skills (22). Family member participants answered using this tool about their older adult loved one. Once scored, a higher score on the RNL indicates greater reintegration to normal social living. These results from this scale provided further insight into the perceptions of the family member on the older adult's level of normal social living during transition into long-term care. Test reliability for the RNL was moderate with an interclass correlation (ICC= 0.83). Test validity was rated adequate with a construct validity for combined sensory index (CSI = 0.50) (22). (See Appendix B).

One primary survey was developed by the principal investigator as a measurement tool: *Survey for Identifying Stressors Present for an Older Adult Transitioning from the Community into Long Term Care*. (Appendix B). This survey gathered information from the family members of the older adult moving from the community into a long-term care facility. This survey provided insight into the negative stressors present for an older adult in this transition.

Data Collection

Prior to the start of each interview, written informed consent was obtained (Appendix A). The initial survey was conducted with both measurement tools (Appendix B) over a one month timeframe. Researcher verbalized surveys to family member participants in a face-to-face interview. Survey interviews were recorded using a digital recorder with consent from the participant.

All surveys were conducted in a private room at the senior facility to ensure confidentiality of survey information. Survey interviews took approximately 20 minutes to complete with each family member participant. Questions focused on past, present and future events related to moving their older adult family members into the long-term care facility. Interviews were conducted by the researcher who has spent 3 years in the participating senior center prior to the start of the study as a recreation therapist.

Data Analysis

The two measurement instruments (survey to identify stressors and RNL) were scored and recorded. Survey to identify stressors results produced qualitative data which were coded and analyzed. Results of the interviews with family member participants were logged and computed through the IBM Statistical Package for the Social Sciences (SPSS) statistics software.

Data were analyzed through descriptive analysis, Pearson's correlation coefficient, and analysis of variance (ANOVA). Descriptive analysis was first completed to analyze data for each specific measurement tool to find the summarization of coefficients in the data set. Further analysis through Pearson's correlation coefficient and analysis of variance (ANOVA) was included to determine the impact of stressors on daily normal living at the point of transition into long-term care.

Results

A total of 39 family members were recruited to participate in the study with a total of 30 completing the study. Seven of the family members did not participate after being approached due to scheduling conflicts with setting up a survey interview time. Two of the family members had their older adult pass away before the survey interview time could be arranged. No family member participants were estranged from the older adult. All 30 family member participants were from different families and reported perceptions of the move of their one older adult loved one. Relationship to the older adult varied (20 children, 6 spouses, 2 siblings, 1 parent, and 1 granddaughter). The older adults lived in three main settings before transitioning to the long-term care facility, (see table 1). The ages of the older adults ranged from 61 to 99 years old with 50% in their 80s, 33% in their 90s, and 17% in their 60s or 70s. All family member participants reported that the older adult transitioned from the community into the long-term care facility in the past 18 months, well within inclusion criteria. Of the family member participants, 22 reported that the older adult transitioned from the community into the long-term care facility within the past 6 months (73% of sample participants).

Table 1. Place Living Before Transition to Long- Term Care

| | Frequency | Percent | Cumulative Percent |
|-----------------|-----------|---------|-----------------------|
| Alone | 13 | 43.30 | 43.30 |
| With Spouse | 13 | 43.30 | 86.70 |
| Assisted Living | 4 | 13.30 | 100.00 |

The initial survey results, *Identifying Stressors Present for an Older Adult Transitioning from the Community into Long Term Care*, reported perspectives of the family member participant during the one month period before the older adult moved to the long-term care facility. The family member participants were encouraged to think back to the last month that the older adult lived in the community when answering the survey questions. Of the family member participants, 87% lived within an hour drive of the older adult. The family member participants reported that 67% assisted with activities of daily living and independent activities of daily living (ADLs and IADLs) such as cooking, shopping, cleaning, transportation, and house upkeep at least once a week. The family member participants reported that 78% of the older adults experienced a hospitalization at least 1 or 2 times within one month before moving to the long-term care facility. Of the sample population, 50% of the older adults had been a rehabilitation client at this senior facility previously and therefore were familiar with the senior facility. Only 1 family member reported their older adult had long term care insurance. The family member

participants reported that 63% of the older adults had moved at least 5 or more times in their lifetime before moving into the long-term care facility. The family member participants reported that their older adult moved to long-term care based on factors listed in order of importance: unable to physically care for self, falls, decline in mental status, lack of social support, lack of financial management, and the older adult chose to move to long-term care facility. The reason for the move into long-term care ranged in means from 1.87 to 5.43. The lower the mean, the higher the level of stress perceived and the higher the mean, the lower the level of stress perceived during the transition, (see table 2). Unable to physically care for the self was listed in the top 3 priorities for all participants. The family member participants stated that the decision to move into long-term care was a shared decision between themselves and the older adult for half the sample size (50% of the time). Furthermore, 50% of the family member participants perceived that the move into long-term care from the community was a negative life stressor on the older adult (see table 3).

Table 2. Reason for Move into Long-term Care Facility

| | Mean | Std. Deviation |
|------------------------------------|------|----------------|
| Unable to physically care for self | 1.87 | 0.78 |
| Falls | 2.37 | 1.22 |
| Decline in mental status | 2.93 | 1.26 |
| Lack of social support | 4.17 | .91 |
| Lack of financial management | 4.23 | 1.61 |
| Older adult chose to move here | 5.43 | 1.31 |

The table below presented the results of the survey to identify negative stressors. The results of the table indicated the percent of the mean for the overall sample size, children only, spouse only, and other family members (see table 3). The table displayed the importance that the type of family member participant may change the perceptions of the stressors present during the move. For example, the children perceived that falls was the primary reason for the move into long-term care, whereas not being able to care for the self at home was perceived by the spouses to be the primary reason for transition into long-term care.

Table 3. Results of Survey for Identifying Stressors Present for an Older Adult Transitioning from the Community into Long Term Care by Family Member Type

| Survey Questions | Percent of Mean Overall (30) | Percent of Mean Children (19) | Percent of Mean Spouses (8) | Percent of Mean Other (3) |
|---|------------------------------|-------------------------------|-----------------------------|---------------------------|
| Live within an hour of the older adult | 87% | 89% | 100% | 100% |
| Assist with ADLs once a week | 67% | 74% | 63% | 33% |
| Hospitalizations (x1-2) in past 12 months | 78% | 84% | 75% | 33% |

| | | | | |
|---|---|--|--|---|
| Rehab client previously | 50% | 74% | 25% | 0% |
| Long term care insurance | 3% | 0% | 13% | 0% |
| Moved more than 5 times in lifetime? | 63% | 68% | 50% | 67% |
| Deciding factor to move to long-term care? (please prioritize these items 1 st , 2 nd , 3 rd) | 1. Unable to physically care for self 2. Falls 3. Decline in mental status 4. Lack of social support 5. Lack of financial management 6. Older adult chose to move here | 1. Falls 2. Unable to physically care for self 3. Decline in mental status | 1. Unable to physically care for self 2. Falls 3. Decline in mental status | 1. Unable to physically care for self 2. Decline in mental status 3. Older adult chose to move here |
| Shared decision to move | 50% | 58% | 38% | 33% |
| Negative life stressor to move | 50% | 42% | 63% | 67% |

Table 4. *Reintegration to Normal Living (RNL)* Index Results by Question

| | Mean | Std. Deviation |
|---|-------|----------------|
| RNL Overall Results | 56.17 | 17.82 |
| Was comfortable with themselves when in the company of others. | 81.67 | 25.74 |
| Was comfortable with their personal relationships. | 81.00 | 27.34 |
| Participated in social activities with family friends and/or business acquaintances as was necessary or desirable to them. | 72.00 | 31.06 |
| Comfortable with how their self-care needs (dressing feeding toileting bathing) were met. | 70.53 | 34.51 |
| Moves around their living quarters as they felt necessary. | 66.67 | 32.68 |
| Able to participate in recreational activities (hobbies crafts sports reading television games computers etc.) as they wanted to. | 57.83 | 34.08 |
| Assumed a role in their family which meets their needs and those of other family members. | 54.00 | 37.66 |
| Felt that they could deal with life events as they happened. | 52.83 | 34.73 |
| Moves around community as he/she felt necessary. | 36.50 | 33.04 |
| Spent most of their days occupied in work activity that was necessary or important to them. | 31.67 | 36.04 |
| Was able to take trips out of town as they felt necessary. | 13.20 | 29.01 |

The higher the RNL score, (see table 4) the more socially reintegrated to normal living was the older adult while in the community as perceived by the family member. This score presented the level of physical, psychological, and social characteristics of an individual so that the older adult can resume well-adjusted living after the incapacitating onset of illness, disorder,

or trauma (22). The average RNL score for the sample was 56 (min: 26, max: 98, sd: 17.82) (see table 4)

Associations between values contribute to understanding the family member perceptions of factors that led to transition into the long-term care facility. These provide understanding of the possible presence of negative stressors during this transition period for an older adult based on the insight provided by the family member participants. An ANOVA test examined the difference between the type of family member participants and the age of the older adult. The family member participants were split into two groups for this analysis: children and non-children. Significance was found as children tended to care for the older aged adults whereas non-children tended to care for older adults who are younger in age ($f = 5.80$, $df = 9$, $p = 0.01$) (see table 5). A Pearson's correlation analysis examined the relationship between the family member perceiving that the older adult was satisfied with how their self-care needs were met and participating in recreational activities. Although not significant, there was a positive relationship for this analysis ($p = 0.16$, $r = 0.40$) (see table 6).

Table 5. Significant Relationship for Children Caring for Older in Age and Children, Spouses, and Parents Caring for Younger in Age

| | Sum of Squares | df | Mean Square | F | Sig. |
|----------------|----------------|----|-------------|------|------|
| Between Groups | 1699.56 | 9 | 188.84 | 5.80 | .01 |
| Within Groups | 651.14 | 20 | 32.56 | | |
| Total | 2350.70 | 29 | | | |

Table 6. Pearsons Correlation for satisfaction in self-care needs (RNL4) and participation in recreational activities (RNL6)

| | | RNL4 | RNL6 |
|--------|---------------------|------|------|
| RNL4_1 | Pearson Correlation | 1 | .40 |
| | Sig. (2-tailed) | | .16 |
| | N | 30 | 30 |
| RNL6_1 | Pearson Correlation | .40 | 1 |
| | Sig. (2-tailed) | .16 | |
| | N | 30 | 30 |

The following Pearson's correlations showed no significant relationship but still contribute to understanding the family perceptions on the transition for the older adult to long-term care. There was no significance in relationship between the age of the older adult and the number of hospitalizations ($p = 0.27$, $r = 0.14$). There was no significance in relationship between the age of the older adult and the older adult being satisfied with how their self-care needs were met ($p = 0.36$, $r = 0.56$). No significant difference was reported in an ANOVA analysis for differences in

prior living situation (alone, with spouse, or assisted living) and older adult participating in recreational activities ($f = 0.16$, $df = 2.00$, $p = 0.86$).

Discussion

Results of this study show that the family member participants who are children (sons and daughters) tend to care for the older aged adults whereas siblings, spouses, and parents tend to care for the older adults who are younger in age. The RNL score measured the family perceptions on the older adult's ability to reintegrate into normal living. The average RNL score of 56 displays that older adults living in the community are not all exhibiting behaviors of daily normal living. Stressors were present in the lives of the older adults as perceived by the family member participants in this study. The most significant stressor perceived by family members was the older adult not being able to care for themselves in the community, as also reported in family members assisting in activities of daily living at least once a week. These two stressors coincide with prior research which stated that low levels of perceived wellbeing for the older adult led to transition into long-term care (13). Other factors for stress for the older adult were reported as recent hospitalizations, lack of long-term care insurance, and lack of shared decision between family member and older adult for the move. Identifying the negative stressors in the transition from the community to a long-term care facility points to the need for more immediate intervention to address these stressors perceived by the family members. Further stress management interventions for the older adults may increase sense of wellbeing to yield the highest levels of quality of life while living in the long-term care facility.

A further finding from this study is that the family member participants perceived that the older adults who were more comfortable with how their self-care needs were being met were in return more able to participate in recreational activities as they desired in the community. This result points to the importance of providing care for older adults through proper self-care and nutrition before the older adult can partake in recreational activities. This was also shown in the survey results showing the primary reason for the older adult needing to move to long-term care was being unable to physically care for the self. If an older adult cannot take care of their basic needs, recreation and leisure will be of less importance. Recreation therapists can utilize these results to consider creative ways to team with other health care professionals to ensure that older adult's self-care needs are being met before attempting leisure education sessions for community dwelling older adults. If an older adult cannot care for their personal needs, they are much more reluctant to participate in recreational pursuits as shown in these study results. The disengagement theory, a social theory of aging, further support and explain these results. The social theory of aging is based on the hypothesis that older people, because of inevitable decline with age, become decreasingly active with the outer world and increasingly preoccupied with their inner lives, which results in the transfer of power from the older adults to those who care for them. From this research, the older adults experienced an increased need for self-care help in the community which resulted in more dependence on family members to help meet basic needs instead of engaging in recreational activities.

Although data collected in the survey interviews provided insight into the transition process, limitations existed in the small sample size of 30 family member participants in this study. The findings could have further significance with a larger sample size. In addition, the variety of diagnoses of the older adults transitioning to long-term care created disparities in data results. The family member's perceptions for an older adult with dementia that had been progressing over the years was observed by the researcher to be drastically different than an

older adult who was moved to a long-term care facility after a traumatic onset such as severe stroke or spinal cord injury from a car crash. Therefore, the family member perceptions were very different between the progressive diseases (dementia, muscular sclerosis, chronic neuromuscular disorders, Parkinson's disease) and the sudden onset of disability. Challenges with the data in this study also existed in the presence of outliers of the sample population including a younger aged older adult who transitioned to long-term care from unmanageable behaviors associated with an eating disorder. In addition one older adult was an outlier who depleted her financial funds and transitioned into the long-term care facility because she could not afford to live elsewhere.

Another limitation to address was positive in nature but a challenge for this study. The senior living center where data collection occurred had a national ranked assisted living facility associated to it, at which four of the older adults lived in before moving to the long-term care facility. Therefore, the older adults transitioning from the high-quality assisted living were observed to come to long-term care with more access to self-care help and recreational activities than the older adults living alone in the community. A further challenge existed with the nature of the research survey questions themselves that created some emotional experiences for family member participants. Three of the family member participants expressed signs of stress and two participants expressed signs of anger at survey questions, showing their perceived personal stress in the transition of their older adult into the long-term care facility. Two family member participants stated they perceived the transition was more difficult and stressful for them, as the support to the older adult, than for the older adult. This showed the need for further research for family members themselves on their perceived stress as their older adult transitions from the community into long-term care.

Based on the results of this research, further studies are needed to examine the perceived stress levels for an older adult in transition from the community into long-term care. The older adults who are younger in age could benefit from further stress management or coping skills interventions during the transition period. Many health care professionals may be able to provide these stress management services, including recreational therapists (23). In addition, family members of the older adults could also benefit from further research on studying their perceived stress while helping their loved one move into a long-term care facility from the community. A recreation therapist implementing a therapeutic group with a social worker may provide unique therapeutic stress management interventions for family members who have an older adult transitioning into a long-term care facility that focus on engaging in meaningful recreation.

With the significant impact and growing numbers of older adults transitioning into long-term care facilities, the need for further research on effective interventions for coping with stress during the transition is key to achieve the highest quality of life for the large number of "baby boomers" approaching their golden years. The potential impact on stress levels of an older adult transitioning into long-term care warrants further exploration and research.

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Appendix A

INDIANA UNIVERSITY STUDY INFORMATION SHEET FOR Family Perceptions on Stressors Present for an Older Adult when transitioning from the Community into a Long-Term Care facility

You are invited to participate in a research study to identify negative stressors present for older adults transitioning from the community into a long term care facility and the strain placed on family members during this transition. You were selected as a possible subject because you are a family member of an older adult who has made this transition into a long term care facility in the past three years. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

The study is being conducted by Dr. Jennifer A. Piatt who is a professor and Coordinator for Recreational Therapy Graduate Program at Indiana University. Kaitlin E. Daly is a graduate student at Indiana University and will be the co-investigator for the study.

STUDY PURPOSE

The primary specific aim of this study is to determine what stressors are present for older adults in transition from the community into long term care through the perceptions of a family member.

PROCEDURES FOR THE STUDY:

If you agree to be in the study you will be asked to do the following things:

You will be asked to meet with Kaitlin, the co-investigator of the study, for a 20-30 minutes interview to answer questions using three surveys. The first survey is called the *Survey for Identifying Stressors Present for an Older Adult Transitioning from the Community into Long Term Care*. This 7-question survey will gather information about your older adult during the time of transition into the long term care facility. The second survey is called the Reintegration to Normal Living Index. This 11-question survey will analyze how your older adult family member responded to illness and living a normal life in the community before the transition. The two surveys will be asked in a quiet, private area of the senior center to ensure confidentiality and openness for conversation. The survey interview will take place without your older adult resident present.

The total time for participation in this study is approximately 20-30 minutes of interview time.

CONFIDENTIALITY

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Your identity will be held in confidence in reports in which the study may be published.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the study investigator and his/her research associates, the Indiana University Institutional Review Board or its designees, the study sponsor, and (as allowed by law) state/provincial or federal agencies, specifically the Office for Human Research Protections (OHRP) who may need to access your medical and/or research records.

PAYMENT

You will not receive payment for taking part in this study.

CONTACTS FOR QUESTIONS OR PROBLEMS

For questions about the study, contact the researcher Jennifer Piatt at (812) 855-7819 or Kaitlin Daly (216) 831-6500 x113. If you cannot reach the researcher during regular business hours (i.e. 8:00AM-5:00PM), please call the IU Human Subjects Office at (317) 278-3458 or (800) 696-2949.

For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IU Human Subjects Office at (317) 278-3458 or [for Indianapolis] or (812) 856-4242 [for Bloomington] or (800) 696-2949.

VOLUNTARY NATURE OF STUDY

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with Menorah Park or Indiana University.

SUBJECT'S CONSENT

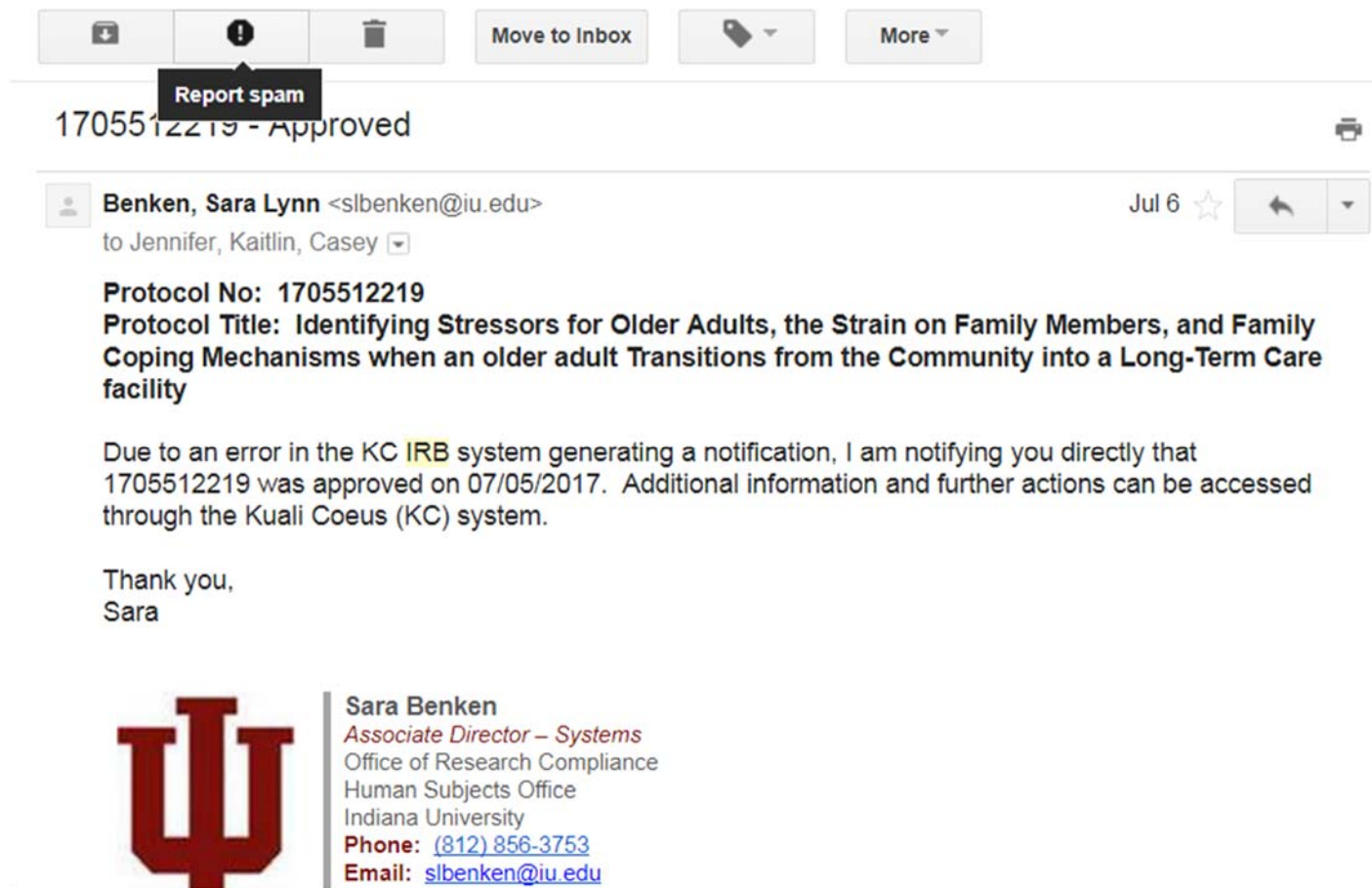
In consideration of all of the above, I give my consent to participate in this research study.

I will be given a copy of this informed consent document to keep for my records. I agree to take part in this study.

Subject's Printed Name:

Subject's Signature: Date:

Indiana University IRB Approval E-mail:



Masters Thesis Research Approval
Kaitlin Daly
through Indiana University by Dr. Jennifer Piatt
IRB Initial Review

May 31, 2017
Richard Schwalberg
Administrator
Menorah Park
27100 Cedar Road
Beachwood, Ohio 44122

This summer I am starting my master's thesis research project in order to complete my degree at Indiana University. Through my work as a recreation therapist in the activities department the past 3 years, I have been able to help many older adults through their transition from the sub-acute rehabilitation pavilions back into the community. However, I have observed that many of our clients choose to remain at Menorah Park as a long-term care resident. During this time I have observed changes in mental processing and stress levels for both the clients and family members of the older adult in transition. This sparked my interest in my thesis research titled: *Identifying Stressors for Older Adults, the Strain on Family Members, and Family Coping Mechanisms when an older adult Transitions from the Community into a Long-Term Care facility*

I am seeking approval from Menorah Park to conduct a three-month research study by way of survey interviews with family members of the older adults who have transitioned into LTC in the past three years. The surveys will be conducted with the family members in a private area of Menorah Park (ideally the resident's room) without the LTC resident present. The survey interview will last between 20-30 minutes per family member. Number of family member participants in the study could equal 60 but may be less based on time constraints and study criteria. The surveys would be conducted outside of my paid time as the rehab activities coordinator.

The documents attached are the abstract for the thesis research study and the three surveys that I will ask the family member participants during this study.

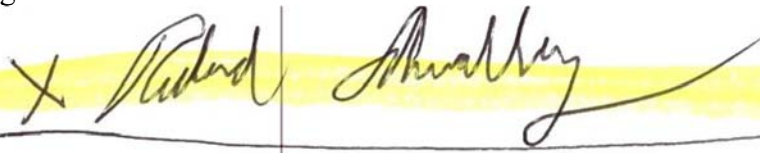
The IRB pre-approval process through Indiana University states that this study is an exempt status and will be approved for being *minimal risk*.

If you have any questions, please contact me at x113 or by email at kdaly@menorahpark.org

Sincerely,
Kaitlin Daly, CTRS

By signing below, you are giving permission to conduct this research at Menorah Park through the month of September 2017.

Signature of Menorah Park Administrator:

A handwritten signature in black ink, appearing to read "Richard Schwalberg", is written over a horizontal line. The signature is written on a yellow rectangular background that has been highlighted. To the left of the signature, there is a large "X" mark.

Appendix B (Study Materials)

Demographics:

Field Notes:

Name of Participant:

Relationship to Resident:

Name of Resident:

Age of Resident:

Admission date of Resident to MP:

Place to Living before LTC:

Which family members
provided care prior to admission to LTC?

Survey for Identifying Stressors Present for an Older Adult Transitioning from the Community into Long Term Care

Please answer thinking back to the time period one month prior to admission into this long term care facility.

2. Do you or your support family members live within an hour drive of the older adult?

Yes No

3. Do you assist with independent activities of daily living (cooking, shopping, cleaning, house upkeep) at least once a week?

Yes No

4. How many hospitalizations in past 12 months for the older adult prior to move into long term care?

1 2 3 4 5+

5. Has the older adult been a rehab client at this facility previously?

Yes No

6. Does the older adult have long term care insurance?

Yes No

7. How many times has this older adult moved in his/her lifetime?

1 2 3 4 5+

8. How was it decided that this older adult more into a long term care facility?

(please prioritize these items 1st, 2nd, 3rd)

Falls Decline in mental status Lack of social support

Unable to physically care for self Lack of financial management

Older adult chose to move here

9. Was the decision for this older adult to move into long term care a shared decision?

Yes No

10. Would you consider the older adult's move into long term care a life stressor?

Yes No

The Reintegration to Normal Living Index (RNLI)

Overview: Wood-Daughnee et al developed the Reintegration to Normal Living Index (RNLI) to evaluate the global function status of a patient during rehabilitation. The instrument can be used to evaluate the degree to which the patient has been able to return to a normal life. The authors are from McGill University and Montreal General Hospital.

Please answer thinking back to the time period one month prior to admission into this long term care facility.

Questions:

1. The older adult moved around their living quarters as they felt necessary.

11. The older adult moved around my community as they felt necessary.

12. The older adult was able to take trips out of town as they felt necessary.

13. The older adult was comfortable with how their self-care needs (dressing feeding toileting bathing) were met.

14. The older adult spent most of their days occupied in work activity that were necessary or important to them.

15. The older adult was able to participate in recreational activities (hobbies crafts sports reading television games computers etc.) as they wanted to.

16. The older adult participated in social activities with family friends and/or business acquaintances as was necessary or desirable to them.

17. The older adult assumed a role in their family which meets their needs and those of other family members.

18. In general the older adult was comfortable with their personal relationships.

19. In general the older adult was comfortable with themselves when in the company of others.

20. The older adult felt that they could deal with life events as they happened.

Scoring is based on distance along a 10 cm visual analogue scale (VAS).

Response Score

no reintegration 0

complete reintegration 10

total score = SUM(points for all 11 items)

adjusted score = (total score) / 110 * 100

Appendix C (Tables)

Table 1. Place Living Before Transition to Long- Term Care

| | Frequency | Percent | Cumulative Percent |
|-----------------|-----------|---------|-----------------------|
| alone | 13 | 43.30 | 43.30 |
| Spouse | 13 | 43.30 | 86.70 |
| Assisted Living | 4 | 13.30 | 100.00 |

Table 2. Reason for Move into Long-term Care Facility

| | Mean | Std. Deviation |
|------------------------------------|------|----------------|
| Unable to physically care for self | 1.87 | 0.78 |
| Falls | 2.37 | 1.22 |
| Decline in mental status | 2.93 | 1.26 |
| Lack of social support | 4.17 | .91 |
| Lack of financial management | 4.23 | 1.61 |
| Older adult chose to move here | 5.43 | 1.31 |

Table 3. Results of *Survey for Identifying Stressors Present for an Older Adult Transitioning from the Community into Long Term Care* by Family Member Type

| Survey Questions | Percent of Mean Overall (30) | Percent of Mean Children (19) | Percent of Mean Spouses (8) | Percent of Mean Other (3) |
|---|---------------------------------|----------------------------------|--------------------------------|------------------------------|
| Live within an hour of the older adult | 87% | 89% | 100% | 100% |
| Assist with ADLs once a week? | 67% | 74% | 63% | 33% |
| Hospitalizations (x1-2) in past 12 months | 78% | 84% | 75% | 33% |
| Rehab client previously | 50% | 74% | 25% | 0% |
| Long term care insurance | 3% | 0% | 13% | 0% |
| Moved more than 5 times in lifetime? | 63% | 68% | 50% | 67% |

| | | | | |
|---|---|--|--|---|
| Deciding factor to move to long-term care? (please prioritize these items 1 st , 2 nd , 3 rd) | 1. Unable to physically care for self 2. Falls 3. Decline in mental status 4. Lack of social support 5. Lack of financial management 6. Older adult chose to move here | 1. Falls 2. Unable to physically care for self 3. Decline in mental status | 1. Unable to physically care for self 2. Falls 3. Decline in mental status | 1. Unable to physically care for self 2. Decline in mental status 3. Older adult chose to move here |
| Shared decision to move? | 50% | 58% | 38% | 33% |
| Negative life stressor to move? | 50% | 42% | 63% | 67% |

Table 4. *Reintegration to Normal Living (RNL)* Index Results by Question

| | Mean | Std. Deviation |
|---|-------|----------------|
| RNL Overall Results | 56.17 | 17.82 |
| Was comfortable with themselves when in the company of others. | 81.67 | 25.74 |
| Was comfortable with their personal relationships. | 81.00 | 27.34 |
| Participated in social activities with family friends and/or business acquaintances as was necessary or desirable to them. | 72.00 | 31.06 |
| Comfortable with how their self-care needs (dressing feeding toileting bathing) were met. | 70.53 | 34.51 |
| Moves around their living quarters as they felt necessary. | 66.67 | 32.68 |
| Able to participate in recreational activities (hobbies crafts sports reading television games computers etc.) as they wanted to. | 57.83 | 34.08 |
| Assumed a role in their family which meets their needs and those of other family members. | 54.00 | 37.66 |
| Felt that they could deal with life events as they happened. | 52.83 | 34.73 |
| Moves around community as he/she felt necessary. | 36.50 | 33.04 |
| Spent most of their days occupied in work activity that was necessary or important to them. | 31.67 | 36.04 |
| Was able to take trips out of town as they felt necessary. | 13.20 | 29.01 |

Table 5. Significant Relationship for Children Caring for Older in Age and Children, Spouses, and Parents Caring for Younger in Age

| | Sum of Squares | df | Mean Square | F | Sig. |
|----------------|----------------|----|-------------|------|------|
| Between Groups | 1699.56 | 9 | 188.84 | 5.80 | .01 |
| Within Groups | 651.14 | 20 | 32.56 | | |
| Total | 2350.70 | 29 | | | |

Table 6. Pearsons Correlation for satisfaction in self-care needs (RNL4) and participation in recreational activities (RNL6)

| | | RNL4 | RNL6 |
|--------|---------------------|------|------|
| RNL4_1 | Pearson Correlation | 1 | .40 |
| | Sig. (2-tailed) | | .16 |
| | N | 30 | 30 |
| RNL6_1 | Pearson Correlation | .40 | 1 |
| | Sig. (2-tailed) | .16 | |
| | N | 30 | 30 |